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ABSTRACT

This feature issue explores health needs of youth with disabilities as they make the transition from child to adult roles. "School Health Services: Supporting Students with Special Health Needs" (Dee K. Bauer) describes the role of the special needs nurse on multidisciplinary teams in Multnomah County (Oregon) schools. Two articles deal with training of health professionals: "Pediatric Residency Program: Providing Training in Transition Issues" (Peter A. Blasco) and "Children with Special Health Care Needs: Advanced Training for Nurses" (Pat Tommet). Other articles include: "Pursuing Healthy Lives: Strategies for the Transition Years" (Deborah Spitalnik and others); "Health Concerns for Teens: A Developmental Perspective" (Peggy Mann Rinehart and Nancy A. Okinow); "Sexuality and Young Adults with Developmental Disabilities" (Leslie Walker-Hirsch and Gitta Acton); "Alcohol and Drug Use by Youth with Developmental Disabilities" (Marty Cushing); "The Parent Case Management Program: Empowering Teens and Families" (Marijo McBride); "Six Characteristics of Quality Health Care" (Barbara J. Leonard); "Joining Ethnic Sensitivity with Family-Centered, Community-Based Care" (Peggy Mann Rinehart); "Partners in Policymaking: Training Policy Advocates" (David Hancox); "Health Care Reform: The Impact on Persons with Disabilities" (Anne L. Henry); and "Family Voices: Speaking Out on Health Care Reform" (Polly Arango). A list of print and media resources concludes the issue. (JDD)

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Feature Issue on Health Needs of Transition-Aged Youth

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Feature Issue on Health Needs of Transition-Aged Youth | Volume 7 (2) Fall 1994

Pursuing Healthy Lives: Strategies for the Transition Years

by Deborah Spitalnik, Anne E. Brady, and Robert C. Like

As the Congress and the nation struggle to enact health care reform, there is deep concern within the disability community about ensuring that the needs of children and adults with developmental and other disabilities will be met. In addition to the activism and advocacy that must be applied to the designing of health care reform, young adults and their families also need to apply activism and advocacy in participating in their personal transition to adult health care, however the larger delivery system is structured.

While it often seems that decisions affecting individual lives, especially in the vital area of health care, are made by systems over which we have little influence, there are strategies that individuals can pursue to enhance their own health and shape the service they receive from providers. We offer to parents and other caregivers the following as suggestions for maintaining healthy lives during adolescence and young adulthood:

The teen years are a time of transition from child to adult roles for youth with developmental disabilities, which includes assuming greater responsibility for maintaining their own health and well-being.

- **Foster healthy lifestyles and wellness behaviors for youth and young adults.** A family lifestyle that takes a positive approach to exercise, diet, and other aspects of health promotion can provide an environment that is supportive of health. For adolescents, peer relationships and modeling are of the utmost importance. Many adolescents with disabilities, even those who are included in regular education, may be very isolated socially as the developmental tasks of adolescence accentuate the challenges posed by disability. The development of active lifestyles, through participation in activities with one's age peers, is an important component of good physical and mental health and health promotion for adolescents and young adults with developmental disabilities.

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From the Editors

As youth with developmental disabilities move into their teens and early 20s - the transition years - their role in identifying and meeting their needs shifts toward increased responsibility and independence. One of the areas in which they are making this transition from child to adult roles is in addressing their health and health care needs. That is the focus of *IMPACT: Feature Issue on Health Needs of Transition-Aged Youth.*

Among the themes carried through the articles in this issue of *IMPACT* are the change in roles for youth as well as their parents or other adult caregivers as the young person matures; the developmental tasks of teenagers in relation to health; strategies for supporting appropriate, quality health care for teens and young adults; and the impacts of health care reform on young people with developmental disabilities and their families.

It is our hope that in these pages parents and other adult caregivers will find practical ideas for enhancing the quality of care received by youth and young adults, and for supporting the young person's increased responsibility for knowing his/her health-related needs and making sound health-related decisions.

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Health Concerns for Teens: A Developmental Perspective

by Peggy Mann Rinehart and Nancy A. Okinow

As children with chronic illness and disabilities move into adolescence and young adulthood, they and their families experience a number of changes that involve health, education, family, work and community living. Adolescents frequently confront multiple obstacles as they undergo these changes, many of which are the consequences of the normal developmental processes and others that are effects of their disease/disability or the result of society's attitudes and perception of their disability.

In the past 20 years or so, due to advances in medical and surgical care, there have been dramatic changes in the health and survival of children born with chronic illness and disabilities. Today, over 85 percent of children born with a chronic or disabling condition can look forward to living until age 20 and, in fact, well beyond. Concurrently, the prevalence of many disabilities has grown: nearly one in three young people has a chronic condition. While not all of these conditions are life-threatening or serious and most only sporadically limit a person's activities, increasing numbers of young people do have chronic conditions that limit their participation in school, work or play.

While young people with chronic illness and disabilities are most frequently "defined" by their disabilities, they in fact experience many, if not most, of the same issues and problems as their peers without disabilities. These issues include the need for increasing independence, healthy self-esteem, and acknowledgment of sexuality. They do, however, often face additional problems. For instance, during the teenage years youth develop the skills necessary to become emotionally, physically, and financially independent of their families. A chronic condition or disability often places teens in a dependent role, precisely the opposite of their need to exercise increasing control over their lives.

■ Independence

Teens need to learn how to make decisions, and how to deal with success and failure. To encourage independence, parents must be able to shift responsibility to the adolescent. The extent to which an adolescent can become independent, however, depends on the degree of disability, the family's psychological support and financial condition, and the teen's motivation. For optimum development, teens with disabilities need to have access to the same life opportunities as their peers, and they need to have equal opportunity to participate, succeed, and fail in those activities. Like their peers, teens with chronic illness and disabilities need to struggle for independence through experimentation. Young people who are never allowed to strive for independence can become emotionally, socially, and economically stunted and end up as dependent, unproductive, unhappy adults.

Every adolescent with a chronic illness or disability should have an independence plan, ideally begun in childhood. This plan should focus on self-care and social mastery skills as well as on the adolescent's progressive independence from the family (and the family's independence from the adolescent!). Such a plan should include training in decision-making skills, assertiveness, and self-advocacy to assist and empower young people to be in control of their own health care. As soon as possible, children should be encouraged to participate as fully as they are able in their own care. This means providing them with age-appropriate, understandable explanations of their medical conditions and therapeutic procedures needed.

For most teens, planning for the future, dating, having a driver's license, enrolling in school, finding a job, and taking responsibility for personal health care are critical to independence. Youth with disabilities may not achieve each of these milestones; however, regardless of ability, adolescents need goals, education, transportation, health care, and work.

■ Physical Health

Adolescents and young adults with disabilities need health care that takes into consideration their overall primary sexual reproductive health; health promotion, nutrition, and fitness; counseling needs; and social development. Though frequently considered to be unusually healthy, all adolescents have a variety of health care concerns and thus have distinctive health care requirements. Some are age-related, while others are related to their inclination toward risky behaviors and experimentation. Primary health care problems include dental problems, changes in vision, skin conditions, and respiratory and other infections. Youth with disabilities or chronic conditions share many of these same health concerns with their peers without disabilities, and because these aspects of primary care are usually ignored, special attention should be given to assuring that these issues are addressed. In addition, health education should be presented as a basis for a more independent lifestyle. For example, for adolescents with inherited conditions, genetic counseling was probably offered to their parents and must now be offered explicitly to the adolescents to improve their ability to make informed choices.

Parents and families must be helped to appreciate the gradual transfer of responsibility for health care from themselves to the adolescent so that they are able to support and reinforce this process. Physicians and other health care professionals must negotiate health care treatment plans with the adolescent, taking into account preferences and lifestyles.

■ Self-Esteem

Healthy self-esteem, the foundation of emotional health, begins developing well before the onset of puberty, and it is tested as youth with developmental disabilities enter the teenage years. Parents usually play a key role in the development of self-esteem. When parents and siblings treat the young person with disabilities like other siblings without disabilities, when they provide appropriate challenges and expect appropriate responsibilities, their teenagers with developmental disabilities tend to have a better self-image.

One area of life that has a profound effect on self-esteem is a young person's social connections. Social isolation too often is a major consequence of disability for both adolescents and parents. Research has shown that teens with disabilities have fewer friends and less intense friendships than teens without disabilities and they report greater loneliness. Participation in regular classrooms should improve the ability of children and youth with disabilities to function with their peers without disabilities. However, just being near peers without disabilities in the same classroom is not enough. To overcome social isolation, there is a pressing need for more active programs in which the teens' social and academic skills are evaluated as part of an overall strategy to address such problems.

Also tied to self-esteem is body image. Young people with developmental disabilities are as concerned about their physical appearance as their nondisabled peers and need to understand the changes their bodies are undergoing. The normal concerns of teenagers (height, weight, asymmetry in body parts, acne) are concerns that are accentuated among developing teens with disabilities. Teens with disabilities and chronic conditions go through the physical maturation process in much the same way as teens without disabilities, but since some part of their body may already be different from that of their peers they often have low tolerance for other deviations from their idealized body image. Families, health care professionals, and other adults often focus on the disability and ignore these typical developmental needs. A balance must be maintained, however, if the young person is to develop a positive self-image.

■ Sexuality

Sexual development is another aspect of the complex set of social and emotional changes that occur during the teenage years. These changes, even in the best of circumstances, are stressful; they disrupt established patterns of behavior and the relationships that existed during childhood.

Although society is beginning to recognize that young people with developmental disabilities experience sexual curiosity and feelings, issues of sex and sexuality are often ignored by parents, teachers, and health care providers. While communication between parent and teenager on sexual issues is often minimal, for those with disabilities it appears to be even less. The lack of knowledge about the sexuality of people with disabilities has created many myths. Until recently, sexual activity on the part of individuals with disabilities was considered impossible or taboo. Sexuality was thought to be only in the domain of those labeled "healthy." Data suggest that teens with disabilities appear to have the same reproductive health needs and sexual development as other teenagers, yet it seems that the response to these needs is often delayed or omitted by those providing routine health care. A group of adolescents with disabilities interviewed recently illustrates the above mentioned issues. When asked if there were things they didn't feel their doctor addressed, one young woman with multiple physical disabilities responded by saying "I'm 21 years old and I don't know if I can have children." Having seen the same health care provider for most of her life, she still didn't feel comfortable bringing up the subject of sex nor did the doctor. While pediatric settings are appropriate during childhood, young adults with disabilities need health care that addresses adult needs and concerns.

■ Conclusion

Youth with disabilities and their parents face many barriers moving from pediatric (dependent) to adult (independent) health care. In 1993, the National Center for Youth With Disabilities published a survey of 248 directors of public agencies from 50 states who provide programs and support for youth with disabilities. When asked which age group receives programming priority, few responded "adolescents." Some 85% reported that infants and toddlers receive the greatest programming emphasis. No matter how well we understand factors contributing to the successful integration of young adults with chronic illness or disabilities into our society, nothing will change until we place the same value on healthy transition into adulthood that we place on early intervention. We must design programs that address the independence, self-esteem, social inclusion, sexuality and other needs that impact the physical and psychological health of youth with chronic illness and disabilities. As we approach the 21st century, our paradigm must broaden: families along with the health care, public health, education, and social service systems must work together to support the growth and well-being of these young adults.

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Sexuality and Young Adults with Developmental Disabilities

by Leslie Walker-Hirsch and Gitta Acton

In the bad old days, the family of a teenager-to-be with a developmental disability might look bleakly toward the young person's entry into young adulthood. Families might have expected to institutionalize an adolescent as soon as he or she reached puberty. If institutionalization was not an option, families often sheltered the young person at home in the belief that it was "for their own good." Many families of young adults with disabilities who grew up several decades ago could only anticipate adulthood for the young person as a time of loneliness and social isolation or as a frightening time of greatly increased risk of exploitation. Families became fully aware of the youngster's reduced opportunity to achieve full adult status and to joyfully explore the world beyond the family home or institution.

Not any more! Families and others who share in the rearing of young people with disabilities coming of age in the 1990s can anticipate very different prospects for these teens. Instead of the dreary destiny of a generation past, today's youth with developmental disabilities can look forward to a life in the community enhanced by potential employment and socialization opportunities. In turn, a variety of relationship possibilities begin to emerge as the young person ventures into the community: acquaintances, co-workers, friends, family and perhaps even a sweetheart or significant other! How will young people access this exciting future in ways that will promote the enriching social relationships and responsible sexual expression to which they are entitled? What kinds of skills and information will teens with disabilities of today need to succeed in the 1990s and beyond? And what supports can parents and others who share in the nurturing of teens with disabilities provide in assisting the progression from young adult to adult wellness and health?

> Being an "askable adult" who listens to the teenager without lecturing or losing patience is an especially important aspect of successfully guiding a young person through the teen years.

As the future reveals itself, academic and vocational education will only partially prepare young people for their successful transition from a protected childhood toward a more self-sufficient and autonomous adulthood. Social and sexual education is another basic building block that is necessary to assure the well-being of individuals with developmental disabilities in their adulthood.

Parents and others who have the primary child-rearing responsibilities have always been the first sex educators of the children in their care, with or without disabilities. They establish the security of a loving relationship between parent and child, which becomes the basis for trusting in future relationships. Parental figures also provide physical and emotional gratification to their children throughout infancy and childhood and, most importantly, are role models of responsible adult relationships. As children become teenagers and adults, parents and others can work closely with schools, teachers, and other professionals to anticipate the kinds of information and skills that will give young people adequate preparation for their adult life.

Often the arrival of a "first" is the way that families are thrust into sudden awareness of a young person's emerging adulthood: a girl's first menstrual period, a boy's first wet dream, a first kiss, or first direct question about sex can rattle even the most nonchalant adult. Although it is these "firsts" that are viewed with the most trepidation, the physical management and social skills that relate to "firsts" are usually quite basic and consequently the easiest for families or others to teach. This is accomplished through modeling, practice, patience, and reassurance. The wide array of printed resources written especially for young people with disabilities can be most helpful in navigating the waters of these "firsts."

Children's puberty is often right on schedule chronologically, despite a possible developmental delay in acquiring the social awareness to the extent that peers without disabilities may already have. Anticipating "firsts" by preparing a child with skills, knowledge and even practice (i.e. changing a sanitary napkin or buying shaving equipment) is a way that parents can make that child's entry into adolescence a positive experience and a smoother transition for the rest of the family, as well.

As children approach and move through adolescence, they often show an increase in their desire to separate from their parents or other adult caregivers and assert their own individuality and independence. Of course, by this age, pre-adolescents and teens have already had some experience expressing their own unique style. They have already made some decisions that are mostly or fully autonomous, such as what to order at a restaurant, which sweater to buy or how to spend leisure time. Making and carrying out simple decisions where the downside risks are small is important in preparing a young adult for how to make the more serious

and complex decisions regarding adult life.

Teens with developmental disabilities cannot always predict the likely consequences of their decisions. Small decisions that turn out either well or poorly can become the basis for the young person's awareness of his or her need for assistance. Establishing a problem solving/decision making process for complex choices that includes discussion between the teen and a trusted adult or parent is important before difficult decisions about sexual issues are raised. The degree of adolescent involvement and interchange is directly related to the young person's ability to understand what decisions are being made. But, regardless of the cognitive ability of that adolescent, adults have an obligation to listen to the needs or requests that a teen is making. Often, a young person may not be able to ask a question using the right words or terminology because they have had limited experience or little education other than education from their peers. Being an "askable adult" who listens to the teenager without lecturing or losing patience is an especially important aspect of successfully guiding a young person through the teen years. Some adults find it helpful to get advice or assistance from a teacher or a counselor about how to establish more adult ways of including their teenager with a developmental disability in the decision making process. Having a voice in decisions that pertain to a teenagers's life is a factor that contributes positively to a teen's self-concept and self-esteem.

As individuals with developmental disabilities move into their adult lives, the role of sexuality education and skills becomes increasingly important to their quality of life.

As with all adolescents, giving up the privileges of childhood does not occur in a day or a week. And childhood is not always relinquished easily! Young adults with disabilities often take longer than usual (socially) to pass through the transition from child to adult. However, biologically, they are right on target with their nondisabled peers. Consequently, adolescence may last beyond the teenage years; teenagers with developmental disabilities may take longer to complete the developmental tasks of adolescence, so encouragement and support by parents and other adults is very important.

As teenagers separate from their families socially, they have a great need for friendships and romances to support them in their quest for adulthood. Otherwise, loneliness sets in and television or fantasy may become the teen's only social outlet. While parents and others in the teen's life may encourage friendships, they often get nervous when any of these relationships take on a sexual aura. They are concerned about the young person's ability to choose a desirable friendship, maintain a positive social or sexual relationship, and be safe from sexual abuse and exploitation. To an even greater degree they worry about the possibility of sexually transmitted diseases and unwanted pregnancy.

While parental or sibling role models for relationship choices are an asset, direct instruction in relationship selection and the associated social skills that support high quality relationships is usually a great advantage. Often, young adults with developmental disabilities have difficulties discerning the significant aspects of a good relationship. However, direct learning about the most important elements of a good relationship coupled with specific, concrete instruction regarding reproductive choices and prevention of HIV and other sexually transmitted diseases is essential to healthy sexuality. Information and supported social opportunity often yields a safe and satisfying social life. Individuals with disabilities whose functional skills are not likely to develop to a level that would allow them great social independence need and enjoy socialization, too! Settings that correspond with their abilities and activities that are in harmony with their social maturity are the basis for positive social-sexual opportunities. All individuals have different needs and abilities and will require an individualized approach to their sexuality education.

It is unreasonable to think that teens with disabilities will not make any mistakes or errors in judgement about their relationships; certainly, the risks of being in adult relationships are not to be taken lightly. However, this degree of risk can be minimized through education and responsible decision making and must be balanced against the extreme importance of relationships to mental health.

Even though adults may have introduced many concepts of sexuality to their young adults at an earlier age, the concepts will need to be repeated and embellished in different ways at different times in their lives. Little children learn about puberty and the anticipated changes to their bodies; teenagers need to put that information into a new context regarding how adult bodies work. Gaining information about adult reproductive health will foster understanding of social codes and encourage a teenagers's acceptance of this newly acquired body style.

Keeping communication lines about sexuality open between adults and teens starts when children are young. Being an askable adult is particularly important to lay the groundwork for the later-than-teenage years, especially for individuals with disabilities. When advice about annual physical exams, sexually transmitted diseases, contraception or other reproductive health issues is needed, a young adult will already have developed a trusted resource from which to draw: an askable, informed parent or other adult whom they can trust to give them answers.

When teens with disabilities grow into adults, their disabilities do not disappear. They may continue to need help in complex decision-making and support in organizing

Sexuality, continued on page 21

Alcohol and Drug Use by Youth with Developmental Disabilities

by Marty Cushing

The house is quiet. Too quiet. It's two in the morning and she said she'd be home by midnight. Dreadful images fill your mind. Suddenly, a ringing phone breaks the silence. "Mom, I'm at the police station. The party got busted and I got arrested. I was smoking pot, mom...I'm scared."

This scenario is one of every parent's worst fears. A young adult son or daughter gets caught using drugs or causes an accident while drinking. Beyond the immediate crisis, the effects of such an episode ripple through school, job, and family life. "But I told her not to use drugs. I thought she understood."

Experimentation with alcohol and drugs has become an all too common phase in the transition from youth to adult, and young people with disabilities aren't exempt. In fact, there is evidence that many youth with disabilities actually have a higher risk of substance abuse or mental health problems than nondisabled peers. We live in a society "under the influence." It's impossible to open a magazine, drive down a highway or watch evening television without seeing an ad for an alcoholic beverage. We're bombarded with messages that tell us we'll be richer or sexier or have more friends if we drink this or that brand of alcohol. For youth with disabilities, these messages can be especially powerful. Often lonely and isolated from their age peers, they look for ways to "fit in" and belong to the group. And if the group is using alcohol or drugs, this is seen as a requirement for acceptance and friendship.

Experimentation with alcohol and drugs has become an all too common phase in the transition from youth to adult...

All too often, youth with disabilities don't grasp the potential consequences of alcohol and drug use. The needs to belong and be perceived as a competent adult are so strong that little consideration is given to the problems substance use can cause at school or work. They don't fully understand the legal and social impact of drug abuse.

It's important for all parents to talk with their young adult children about the potential consequences of alcohol or drug use. More effective than the preachiness of "just say no" is a parent explaining simply and concretely how trouble with substance abuse can impact one's future educational, vocational or legal status. It might be a good idea to review the penalties if the youth is caught using illegal substances, drives drunk or gets arrested for an alcohol-related offense like disorderly conduct. If the young person has a learning or developmental disability, parents and teachers should provide information about how alcohol or drugs affect thinking, memory, and behavior. Guidelines or rules about what is or is not acceptable need to be as clear as possible.

It's especially important for parents to be strong role models. If alcohol consumption is a routine part of family life, it will be impossible to convince a young person that it's unwise to drink or use mood-altering substances. Even something as "harmless" as opening a six-pack during the football game sends an clear message that drinking is okay.

There are warning signs when a young person is beginning to have problems with alcohol or drug use. There may be unexplained changes in behavior, with more moodiness and withdrawal. Absences from school or work often increase. The young person may be less open about friends or social activities. There might be bruises or other injuries caused by alcohol or drug-related accidents. If parents believe a youth is using alcohol and drugs, the situation should be approached calmly but firmly, with a message of respect and caring.

When a young adult is suspected of abusing substances, evaluation by a qualified counselor is vital. Schools, county social service agencies, and telephone "help-lines" can provide information and referral to local resources. An excellent source of information is the National Clearinghouse for Alcohol and Drug Information at (800) 729-6686. This is a federal service available to people throughout the country. If a young person with a disability is referred to a treatment program, it's critical that the counselors know about the disability and get advice about accommodations that may be necessary.

Keeping youth with disabilities drug-free is a challenging task, and requires the cooperation of parents, teachers, employers, and friends. Young people who abstain from alcohol or drugs have less difficulty making the transition from teen to adult. But, they are still faced with pressures to use chemicals and they need adult guidance to make it through the transition years "clean and sober." Youth with disabilities face enough hurdles; substance abuse doesn't have to be one of them.

Marty Cushing is Executive Director of the Vinland Center, a rehabilitation agency located in Loretto, Minnesota. Vinland provides a range of services for people with disabilities, including chemical health treatment for persons with cognitive and functional disabilities. FFI call (612) 479-3555.

Recovering and Proud: Ricky's Story

When Ricky Barker was buying beer for kids from his old high school, he didn't stop to think that most of them were under 21. He was just being friendly. And when Ricky got fired from his job at a local restaurant, he didn't realize that the reason - excessive absenteeism - might have been due to hangovers. It took an arrest and the unified efforts of the court, his case worker, and his friends for Ricky to understand that he had a problem with alcohol.

Ricky Barker also has a developmental disability. His test reports call it "mild mental retardation." He spent the first 10 years of his schooling in segregated, special education classes. In ninth grade, Ricky was integrated into the general student population in a northern Minnesota high school. Although he still attended specialized math, reading, and language classes, he spent over half his day in "mainstreamed" classrooms.

Ricky found his way to parties that were attended by teens from his old high school. He discovered they liked being around him when he was able to buy them liquor or beer. For the first time in his life, Ricky was making friends with the "regular kids."

Ricky loved being "just like the other kids." He enjoyed his integrated art, physical education, and home economics classes. But he quickly learned that being mainstreamed had a dark side. "The kids didn't like me being in special ed. When I came out of the special ed room, they teased me." Later on, because he wasn't able to drive, he got left out of a lot of teen activities. Although he was pleasant and friendly, Ricky felt alone and ashamed.

Home life wasn't any easier. During his teenage years, Ricky's mom died from an alcohol-related illness. So as a young adult, when he found himself lonely and depressed, it was no surprise that he turned to alcohol to ease the pain. Ricky found his way to parties that were attended by teens from his old high school. He discovered they liked being around him when he was able to buy them liquor or beer. For the first time in his life, Ricky was making friends with the "regular kids." His new friends were so important that Ricky sometimes skipped meals or buying clothes so he had money for liquor. In the end, he was spending over half of his monthly income on alcohol.

After he was arrested for supplying alcohol to minors and lost his restaurant job, it became clear to his caseworker that something had to be done. When an attempt at outpatient treatment failed, Ricky agreed to enroll in the residential chemical health program at the Vinland Center near Minneapolis. Vinland's program specializes in serving people with cognitive and functional disabilities.

At Vinland, Ricky learned that drinking alcohol can cause countless health and social problems. He discovered how drinking made him less able to take care of himself, making his goal of independence harder to achieve. He got help finding new hobbies and leisure opportunities to replace the alcohol-related activities he'd been focused on. He was introduced to Alcoholics Anonymous (AA) and learned how AA works.

After several weeks at Vinland, Ricky was ready to return home. Before going back out on his own, he spent time in a half-way house. There he continued to get support for his sobriety and reinforcement for his new social and leisure skills. Now Ricky is living in his own apartment and receiving supported living services. He has a new job and is doing well. His work evaluations have been excellent and he continues to be sober.

Quitting drinking didn't solve all Ricky's problems. Life still has it's ups and downs. A year ago, he got married to a woman he'd met in a vocational rehabilitation program. It didn't work out; the couple is separated now. Ricky still experiences loneliness and stress, but his new sober friends and a committed AA sponsor help him work through the rough spots.

Ricky still experiences loneliness and stress, but his new sober friends and a committed AA sponsor help him work through the rough spots.

Over time, the real Ricky Barker is emerging. He is a young man with a warm and outgoing personality. He is gaining competence in his independent living skills and is confident about his future. He is gentle and kind. And he is proud. He is proud to be working. He is proud to be living on his own. He is proud to be sober.

By Marty Cushing, Executive Director, Vinland Center, Loretto, Minnesota.

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School Health Services: Supporting Students with Special Health Needs

by Dee K. Bauer

In the 1990s, the path through the teen years for youth is full of new and difficult challenges, and, if you are a teen with special health needs, walking that path is easier with a friend at your side. Pre-teens, teens, and young adults who attend one of the 150 schools in Multnomah County, Oregon, can find such a friend in the school nurse.

School Health Services, a department of Multnomah Education Service District, provides a variety of school health services including school nursing and nurses who are assigned to students with special health needs in the public school setting. When a student is enrolling or transferring into this system, and is identified by self or family as having some unique and special health needs, a member of the multi-disciplinary team will be a special needs nurse from the Department of School Health Services.

Referrals for assistance may come from the school nurse, the student, parents, district intake personnel, physicians, or teachers. When special needs nurses receive a referral, an initial parent contact is made. Visiting at home with parents, student, and family is a way for this nurse, who specializes in working with students with unique health needs, to gather history, concerns, suggestions, insight, and a general understanding of the strengths of the student and parents or areas needing assistance.

The special needs nurse meets with others involved with the student and his or her family, even occasionally accompanying the student to a clinic or physician appointment. Conferring and consulting with other health care providers, and coordinating the efforts from this discipline into the school setting, becomes a case management role for the special needs nurse. The school site proposed for student placement is evaluated for possible barriers, needs for adaptation in the environment, access, and support. The special needs nurse obtains physicians' orders as required, meets with the multi-disciplinary team to give input into appropriate placement, and develops a plan of care called a Student Health Management Plan, to address the health needs of the student, prior to his or her beginning school.

If the student needs assistance with particular health procedures during the school day, the special needs nurse, under rules allowed by the State of Oregon, may select individuals to whom are delegated certain tasks of nursing care. This delegation is done with input and cooperation from the student and parent. The nurse selects a classroom individual who would be able to assist the student as part of the school day. After discussing with the school administrator and others the need for privacy, time, and support, the special needs nurse begins the training of the delegated caregiver. Delegated caregivers must demonstrate sensitivity, willingness to assist, and skills and competency to follow through on any delegated nursing task. After a demonstration of the actual task and written instructions regarding specific health needs, a delegated caregiver must demonstrate to the nurse competencies in carrying out this procedure. He or she also must indicate in writing the understanding that this procedure is to be for a specific student only and may not be generally applied to other students. The nurse maintains primary responsibility for the nursing care, however, evaluating the student's ongoing health status while in the school setting, the student's response to the procedure, and the adaptations necessary, as well as supervising the skills and competency of the caregiver on an ongoing basis. If involvement with a student's health needs requires significant time or assistance, the special needs nurse may turn over the monitoring of the student's health needs and supervision of the caregiver to the regular school nurse.

When a student changes schools or makes the transition from school into a work environment, the special needs nurse provides support. The nurse will work with both the receiving and the sending schools' multi-disciplinary teams to assure that no break in continuity of health care occurs. If the student is in high school and is beginning to do some transitioning into a work site setting, the special needs nurse may work with the transition coordinator and the employer to assure that assistance is available for the young person at the work site.

And always, the focus is to help students assume responsibility for as much of their own health care as possible. Some students have cognitive or physical limitations that will not allow them to be completely independent; others need time, encouragement, assistance and patience. This is the role of the special needs and school nurse: to provide that education, assistance, and encouragement during the school day. And even the student who is fairly independent in management of the health problem may occasionally need the expertise of the nurse when there are changes in health status, procedures or medications.

Today, it is estimated that approximately 20 to 31% of students attending public schools have health problems requiring assistance during the school day. This may range from students who need help managing their diabetes by testing blood sugar and injecting insulin, to the student who is attending school with such severe health needs that he or

she may need a one-on-one nurse to assist and make sure that the student is able to breathe or swallow.

A recent article in the American School Board Journal (March, 1994), addressing medically fragile children in school settings, recommended enlisting medical professionals "to provide hands on training for school personnel to ensure that all are benefiting in caring for the medically fragile child" and "to assign a school nurse or other certified medical person to every school in the district to provide written instruction, technical assistance, and supervision to teachers as well as direct service to medically fragile children." All young people deserve the best opportunity for education. If an additional challenge to achieving that education is a health problem, a health professional such as a registered nurse specializing in health problems of youth needs to be part of the team who helps the student and his or her family through the process. Although school health services are identified as *related services* under IDEA, some schools or school districts do not have access to a school nurse. If students with health problems are to have successful experiences in education and transition into work settings, it is essential that school districts examine their policies regarding hiring school nurses. Nursing has always been the link in the bridge between the medical community, the client, and others. When the "others" are in a school setting, it is more essential than ever that the discipline of nursing be involved to assist students and school personnel.

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Reference: Essex, N., Schifari, J., & Bowman, S. (March 1994). Handle with care. *The American School Board Journal, 181* (3), 50-53.

The Encourage Program: Peers Support Teens with Chronic Illness

For all adolescents, positive peer relationships are critical to healthy development. These relationships provide opportunities for social connections that support the development of a positive self-concept. Peer relationships also encourage the emerging independence so important for entry into adulthood. In addition, teens are more likely to accept from their peers the support, encouragement, and feedback necessary for the development of healthy social and problem-solving skills.

Chronic illnesses, such as cancer, asthma, or diabetes, impose physical limitations, often require repeat medical visits, and can involve complex medical treatments. A chronic illness affects the tasks and transitions of adolescence in many ways. It can complicate the development of independence and connection to peers. It can introduce a new set of emotional conflicts (such as fear, guilt or isolation) during an already emotionally charged time. It may place stress on relationships due to the limits on social activities or increased need for support. And, it can negatively affect teen self-esteem and self-concept.

The Encourage program was developed with an appreciation of the impact of chronic illness on the lives of teens and the importance of peer relationships for those teens. This program at Children's Hospital of St. Paul was designed to help teens diagnosed with a chronic or life-threatening illness to adjust to the changes in their lives through individual contact with a peer with a similar illness. The program trains adolescent and young adult peer helpers to provide support to teens with chronic illness. The intervention capitalizes on the important role teens have with their peers in helping them to learn and develop. Through the program, adolescents receive support by meeting with someone their own age who understands their experience. Peer helpers maintain regular contact with the teen they are supporting through hospital visits, discussion, and/or social activities. They talk about their challenges and share their experiences in coping with a chronic illness.

Through the Encourage program, teens have felt understood and have found support in knowing others who have faced similar life challenges. For some teens, meeting with a peer helper is their first experience getting to know someone their own age with a chronic illness. Their relationship with their peer helper or other teens in the program reduces their feelings of being alone or different. Other teens, who are beginning to incorporate their experiences with their illness into their lives, benefit through increased self-understanding and acceptance of their illness. Knowing a peer who is living successfully with the same illness can help them feel better about themselves. In addition, it has helped them to cope with difficult experiences and feelings that emerge as a result of living with an illness. For many teens, their identification with a peer has fostered more positive expectations for themselves and a greater sense of hopefulness about their own future.

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The Parent Case Management Program: Empowering Teens and Families

by Marijo McBride

In the past, the case management of services for people with developmental disabilities was largely left to professionals. Today, there is a growing recognition that each person with a disability and each family are the true experts on their own situation. It is this premise that guides the activities of the Parent Case Management Program.

The Parent Case Management Program began in 1986 by training and supporting self-advocates and parents/guardians to participate more fully in the case management of services they receive. In 1992, the program expanded to include the training of participants to return to their communities and facilitate training and technical assistance for others. A year later, the program expanded further to establish the Parent Case Management Program for People of Color which, through collaboration with leaders and organizations in the African American and American Indian communities, seeks to be a culturally sensitive tool for the empowerment of participants.

The entire Parent Case Management Program is committed to creating flexible supports that build on the unique capacities of self-advocates and each family, enhance their active participation in determining their own needs and directions, and prepare them to take the leadership role in the identification and management of supports and services they receive. Through offering training, support, information, and technical assistance the program seeks to empower participants in all areas of life, including health care.

In addressing case management needs related to health care, the program assists individuals in becoming knowledgable about the following areas: (1) accessing and processing information about a medical diagnosis, treatment or related issues; (2) health care systems; (3) resources; (4) communication skills; (5) negotiating skills; and (6) record keeping. Participants also develop the confidence and skills to state their needs, concerns, and desires related to health.

In addition to developing knowledge, skills, and confidence, the program encourages family support for the exercise of self-determination by young adults in relation to health issues. This aspect is addressed through sharing of printed information, videos, and presentations, as well as through networking with others for problem solving and sharing ideas. Specific topics that are addressed include:

- Families and self-advocates supporting age-appropriate choice making.
- Risk taking.
- How young adults identify and express their medical needs, concerns, and wishes.
- How young adults can be effective and active members of their medical teams.
- Ways to promote effective, respectful, and positive communication with young adults by health care providers.
- Record keeping and maintenance of medical files.
- Cultural diversity.
- How families can support their young adult member in dealing with medical issues and systems.

The Parent Case Management Program has made a positive difference in people's lives as it relates to medical issues. As one Parent Case Management parent/facilitator has summarized:

> *The Parent Case Management Program has empowered me to help educate the medical professionals about persons with disabilities. I help break stereotypes about African American mothers; people need to let go of their stereotypes ana realize that no two persons or families are the same. We need to look at each person as an individual. I have become a resource to building bridges across systems that my children have contact with. My son's doctor comes to his I.E.P. meeting. This is a wonderful way for medical issues to be addressed and information shared on an equal level with my child's team.*

Evaluation of the Parent Case Management Program indicates that the program impacts people in a number of areas. It provides information for the participants. As a result of the program participants are able to obtain additional services, are more satisfied with the services they receive, and believe that they have improved accountability. It also improves their roles and interactions in the family, as well as their links with social resources and their social network. It provides emotional support to the participants. And it helps them be more self-assured and decisive.

The program has also impacted transition age youth with developmental disabilities by sharing with them health care information, ideas about resources, and networking opportunities. With this knowledge and skills they become aware of choices related to health care and empowered to act on their choices. The outcomes have shown that youth who participate in the program have expanded visions of

their options, greater control over their health care, and an increased feeling of support and empowerment. As one participant stated, he became aware of options, had skills to state what he wanted, and was not discouraged when he ran into roadblocks. As a result, he acquired an electric wheelchair that increased his independence.

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Speak Up for Health: Planning for Transition in Health Care

Planning for the transition to adulthood has many challenges. Traditionally, five areas of transition have been considered as part of the individual education plan (IEP) process: secondary education, community participation, home living, leisure and recreation, and jobs and job training. There is one very important area that affects all the others, but is often omitted or forgotten. This area is health. Knowing about one's own health needs and preparing to take some responsibility for one's own health care is an extremely important part of transition planning. Understanding how health affects one's work, how a school must respond to one's health needs, and how to find a doctor and communicate with health professionals about one's needs are essential parts of living successfully in the community. Planning for transition in health care takes time and should be incorporated in a transition plan as early as possible.

To assist parents in considering their son or daughter's health needs as part of transition planning, PACER Center - a Minneapolis-based training and information center for families of children with disabilities - began the Speak Up for Health project. Through the activities of this project, materials have been developed to give families information and support as they began to plan for transition in health care. Some of these materials include, *Speak Up for Health: A Parent Handbook*, and *Living Your Own Life*, a book written for young people with disabilities by young adults with disabilities, as well as handouts and workshop outlines for parents and adolescents with developmental disabilities.

The project has been successful in helping parents to recognize the need to plan for transition in health care and to recognize the skills that they have learned and the strengths that their son or daughter has that will be helpful in this transition planning. Many parents of teenagers with developmental disabilities have been pleased and surprised at the role their son or daughter could play in their own health care. For example, some teens may not be able to state the names of their medications or know drug allergies - important pieces of information when one goes to the doctor - however, they can carry this information in their wallet. Additionally, parents participating in Speak Up for Health have enjoyed the opportunity to discuss their teen's health care with their son or daughter in a workshop setting. They receive a workbook especially made for teens and information for parents that includes health care skills, a transition plan, and a checklist for residential settings that assists parents in knowing questions to ask when screening a residential setting for their son or daughter (questions include what doctor is affiliated with the residence, what emergency procedures are appropriate for the individual, and what hospital will the individual go to if he or she has an emergency?).

Another important consideration addressed by families in the program is deciding who will care for the health needs of the member with a disability if a parent is not available. One strategy is to assign a health advocate. A health advocate is a family member or friend who will interact with the health care provider on behalf of the person with a severe disability. This person may go to appointments or simply keep up on the health records of the individual with a disability. What is important is that there is someone who is taking care of this aspect of the young person's life as a facilitator who uses all the abilities of the individual with a disability and promotes this individual's fullest possible participation.

Promoting participation in health care is an important part of preparing for the future. Through the Speaking Up for Health program teenagers with disabilities and their families gain the knowledge and tools to make a successful transition from child to adult health care.

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Pediatric Residency Program: Providing Training in Transition Issues

by Peter A. Blasco

Traditionally, medical training has been geared toward acute illness. Pediatric residents only saw children with chronic illness or disability during a crisis. The many transition issues relating to these patients were addressed to a limited and inconsistent degree. In the past four years, the University of Minnesota's pediatric residency program has made an effort to focus and formalize the teaching of transition issues via two required one-month training experiences ("rotations") in adolescent health and developmental disabilities. "Letting go" issues (from both the pediatrician and parent perspectives) and "assuming responsibility" issues (particularly in terms of independence in health care decisions) are the main foci, but many other family issues are covered, as well.

Residents in their second year of training spend four weeks learning about children and young adults with developmental disabilities, their families, and their special health care needs. The residents attend daily medical rounds and work with children and youth hospitalized at Gillette Children's Hospital in St. Paul, and they evaluate young people with a variety of disabilities in outpatient clinics conducted at several Twin Cities hospitals. The age range and patient mix are both broad and include high risk neonates, infants with developmental delays, and older children and adolescents with myelodysplasia, cerebral palsy, neuromuscular disease, learning disabilities, and mental retardation. This spectrum allows residents important glimpses into the continuum of problems and needs over time.

There are four primary goals of the rotation. One is to teach residents the basic facts of developmental disabilities: mental retardation, cerebral palsy, myelodysplasia - all the major disabling conditions and their related problems. Secondly, residents are expected to know and understand child and adolescent development: neuromotor development, cognitive development, and psychosocial and affective development. Highlighting the sequences of normal development and the early recognition of significant deviations is a part of this goal. In the clinical setting, they are taught to account for the child's abilities as well as the disabilities and to address every dimension of behavior and development in order to understand how best to help the child and the family. The third goal is to integrate the neurological and developmental examinations into the resident's clinical repertoire. The fourth goal is focused on communication issues: to enhance the young physician's ability to communicate with families, with other professionals, and with community agencies working with children and youth who have developmental disabilities.

Portions of the month are set aside for the residents to observe children in everyday life situations: at school, at home, going to therapies, playing with friends or with family. They are encouraged to understand the whole child and are guided in learning to be sensitive to the impact a disabling condition has on the entire family. In collaboration with PACER - an advocacy/resource organization serving families with children who have disabilities - residents make home visits to families who have a child or children with disabilities. They learn to value the depth of parents' medical knowledge and their expertise in managing their child's illness or disability. In collaboration with the Institute on Community Integration at the University of Minnesota, residents visit two community agencies serving people with disabilities. Residents learn in concrete terms how these activities enhance each individual's abilities and how the programs fit in over the continuum of the individual's life.

Every Friday morning is devoted to discussion sessions during which the residents meet with a variety of individuals representing a cross-section of health care and advocacy disciplines. They discuss family structure and functioning, grief and loss, personal vulnerabilities, and specific transition issues. During these sessions, residents are presented new frameworks for working with families, and they have the opportunity to reflect on and learn from each other's experiences. Youth themselves are involved in the teaching via an outstanding videotape developed by PACER as part of their transition project. These discussions on transition issues are integrated into the day-to-day clinical experiences. Faculty members make an effort to model approaches to care that go beyond purely medical issues, including all the adolescent-to-adult transition issues.

The concept of collaboration, or partnership, in health care for patients and their families is emphasized throughout the rotation. Helping the child and family clarify expectations and providing them a structured way for thinking through their endless challenges, worries, and decisions is another aspect of the partnership approach. The residents learn the importance of making certain the relevant medical facts are complete, correct, and understandable. The physician's role as an advocate for independence at an early age is another concept that is emphasized. Families need strategies to recognize and to nurture independence early, so it does not become an issue in adolescence. Many of the transition difficulties facing the adolescent are a direct consequence of

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Children with Special Health Care Needs: Advanced Training for Nurses

by Pat Tommet

Caring for children, adolescents, and young adults with special health care needs (a term that includes developmental disabilities and chronic illness) is the focus of the new advanced practice program, Children with Special Health Care Needs, in the School of Nursing at the University of Minnesota. This interdisciplinary training program prepares advanced practice nurse leaders in the care of children, adolescents, and young adults with special health care needs and their families within the context of rapidly evolving health care, human services, and educational systems.

This training program - a collaborative project of the University's School of Nursing, School of Public Health, and Institute on Community Integration - evolved from a focus group needs assessment conducted in 1991 with nurses throughout Minnesota who worked with children, adolescents, and young adults with special health care needs. The nurses reported a lack of knowledge and skills on the part of many nurses related to current trends in services for individuals with disabilities, interdisciplinary practice, biomedical advances, and family-centered services. According to these nurses, the level of knowledge and skill required by nurses to improve health care and nursing services to young people with special health care needs necessitated a formal graduate level education program, rather than a time-limited inservice education program.

The Children with Special Health Care Needs program has been designed to provide both classroom instruction and community-based experiences for nurses. Coursework focuses on current trends in service provision for persons with developmental disabilities, biomedical knowledge, family-centered care practices, ethical issues, interdisciplinary team process, leadership skills, public policy formation, and health care reform. To supplement classroom instruction, nurses have many opportunities to apply their knowledge in community-based, interdisciplinary practice sites located in various hospitals, outpatient clinics, family homes, schools, recreation and leisure centers, and employment settings. Other community-based experiences provide the opportunity for nurses to participate in legislative and policymaking activities with legislators and staff from advocacy and state policymaking agencies. These practical experiences enable nurses to integrate classroom learning with real life experiences.

A key component of this training program is its strong emphasis on the families of children, adolescents, and young adults with special health care needs. To supplement community-based learning experiences, each nurse follows a child, adolescent, or young adult and their family for nine months. They spend time with this young person and family in their home and in the community, learning about family life, health care, school, recreation and leisure, and employment needs. This provides nurses with the opportunity to view life from the perspective of a young person with special health care needs and their family by attending school meetings, health care visits, recreation programs, and by visiting with the family in their home. Through this process, nurses have the opportunity to understand the needs and concerns of the family from their point of view.

Although the Children with Special Health Care Needs program focuses on individuals from birth to 21 years of age, classroom instruction and community-based experiences provide specialized developmental and age-specific content and learning experiences. For example, content specific to adolescents and young adults focuses on developmental processes and issues such as nutrition, exercise, sexuality, dating, citizenship and self-determination in order to prepare adolescents and their families for the transition to adult life. Nurses learn about all of the areas of transition including home living, community participation, recreation and leisure, work and job preparation, and post-secondary training and learning, with primary emphasis on the transition from pediatric to adult health care. Health care transition services emphasize knowledge and skills necessary for self-health care, health care coordination, and service coordination (case management) to prepare adolescents and young adults with special health care needs and their families for the transition to adult life.

The program of study provides a two year combined pediatric nurse practitioner/specialist focus. The first group of nurses admitted to this program entered in the 1993-1994 school year and recently completed their first year of study. So, as yet, there are no graduates. As we begin our second year, we look eagerly to the ongoing collaboration with young people who have special health care needs, their parents and families, and community-based providers in this joint effort to improve nursing and health care services for children, adolescents, and young adults with special health care needs and their families.

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Six Characteristics of Quality Health Care

by Barbara J. Leonard

For youth and young adults with chronic illness and disability, health services ranging from clinic visits to inpatient treatments and home care are an integral part of their lives. For them, especially, identifying and receiving quality health care is essential to their well-being and even their survival. Medical care that is excellent in terms of the technical skills and specialized knowledge of the provider may still not be quality care. Quality care involves more than technical competence. It also encompasses the following six characteristics of the relationship between the provider, patient, and family: Appropriate communication, person/family centered care, continuity of care, comprehensive care, community-based care, and family/individual empowerment.

■ Appropriate Communication

Youth and young adults with special health care needs and their families have the right to appropriate communication from providers. This includes professionals addressing the young person's concerns in a manner mindful of the individual's developmental level, emotional status, and language ability. It also includes providing information in a manner that's understandable and meaningful to the family. For example, explaining a treatment to a family without explaining its implications for the individual's continued growth and development and its impact on the family's daily routines would fall short of helping the family, and may leave them bewildered at best.

Appropriate communication also considers the feelings of the young person and family. Health professionals faced with delivering unpleasant information to a child and family need to be sensitive to their need for privacy, expression of feelings, and emotional support. Giving a diagnosis in a private area with both parents or other supportive persons, presented in an unhurried manner, can aid the individual and family's feeling of control over their lives. Parents who feel understood and supported are more likely to be able to care for their children and work effectively with their health providers.

■ Person/Family Centered Care

Another component of quality health care is that it places meeting the needs of the individual and their family above meeting the needs of the professionals and the health care system. Treatments are adapted to fit the individual's and family's daily routines, within safe limits. An illustration is the scheduling of health care visits for times when the young person is not in school and the parents are not at work. A second example is using medications that can be given twice daily instead of three times to accommodate the young person's school day. Quality care recognizes the need to build both the parent's and child's sense of control and competence in management of the health condition, and focuses on the strengths and assets of the individual and the family, instead of on their deficits.

■ Continuity of Care

Continuity of care has long been a criterion for quality health care. Today, many factors hinder its achievement in a rapidly changing health care system. Continuity of provider(s) and proper transfer from one provider to another are critical to quality care. Young people with special health needs are frequently working with a number of medical subspecialists who, all too often, do not communicate among themselves regarding the individual's care. This leaves the young person and/or the family with unanswered questions and unresolved issues. Given the complexity of medical care, a care coordinator can be appointed to work with the family to assure continuity of services. Many times the family is able to do this for themselves, but in the beginning many may welcome help until they feel well enough informed to take over coordination.

■ Comprehensive Care

Comprehensive care is another aspect of quality health care with important implications for youth and young adults with special health care needs and their families. Attending to a young person's emotional, educational, and social concerns and needs helps to insure developmental progress. Care coordination among health care professionals, educators, and social service providers serves to guarantee provision of comprehensive care. Families will recognize comprehensive care when their annual health visits include a review of the broader dimensions of the young person's life as well as health concerns and progress, and when the plan of care reflects these broader dimensions.

■ Community-Based Care

Whenever possible, the young person and family should receive services within their home community. When individuals are seen at a medical center distant from their home communities, the community-based family doctor must have ongoing communication with the specialists in order to provide appropriate treatment. Parents should not be expected to convey the specialist's recommendations to the family physician or other persons caring for the youth or

young adult in the school or work setting. Medical professionals must communicate effectively with all those involved in providing treatment and care for the young person, and must do so in language understandable by non-medical personnel such as teachers and social workers.

■ Individual/Family Empowerment

There is a growing belief in the value of empowering young people and their families to direct their health care in a partnership with providers. To the extent that the youth or young adult and family members are respected as equal partners in the relationship, quality will be preserved. Professionals will come and go in the life of the young person and family. The latter are the ones who must be empowered to advocate for themselves within the health system, and to take the lead in seeking what is necessary for their child and themselves. Professionals must respect the right of consumers of medical services to "chart" their own care course.

■ Conclusion

Youth and young adults and their families are entitled to the highest quality medical care available within their region. It is incumbent on health professionals to keep abreast of the latest treatments and medications, making them available for their clients either personally or through referrals to other providers. And while quality health care reflects the ever-changing developments in medicine and surgery, as well as related services, it is also based on the principles of good communication and the concepts of consumer-centered, continuous, comprehensive, and community-based care. Excellence in knowledge and technical skill on the part of health care providers do not, by themselves, equal quality health care. They are essential but not sufficient components of this multifaceted concept.

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Primary Health Care Project: Quality Care Through Family Physicians

For the past six years, we have been assisting adults with mental retardation and associated developmental disabilities to receive their primary health care in a large generic group practice in the community. These efforts have come about through a partnership between three programs: the Family Practice Center, Inc. of St. Peter's Medical Center in New Brunswick, New Jersey; the University Affiliated Program of New Jersey at the Robert Wood Johnson Medical School, University of Medicine and Dentistry of New Jersey; and the Department of Family Medicine, also at the Robert Wood Johnson Medical School. Through this partnership, 105 adults have been fully integrated into the Family Practice Center. Every adult has their own family physician with whom they make individual appointments; no specialized time period or clinic has been created. A resource unit provides care coordination, which includes support for these adults with disabilities in receiving care and negotiating other necessary services; support for their families, other caregivers, and provider agencies; and support for the physicians and nurses of the Family Practice Center in providing care. All of the individuals served through this project are on Medicaid as the source of payment for their health care. We are utilizing a Medicaid Health Maintenance Organization, a form of managed care, because it offers the most flexible and adequate reimbursement for the health care services provided.

Health care services for adults with developmental disabilities have traditionally not been as developed nor as family-centered as the expertise found within many pediatric centers. Family medicine, with its emphasis on the family and community context for all individuals and the recognition of the importance of psychological and social factors in health and well-being, has made for a good fit with the person-centered, community inclusion emphases of the disability movement. Training for these family physicians, in addition to providing enhanced information on associated conditions, has stressed the complexities of accessing community services and an understanding of the demands of family life when one member has a disability. We believe that this approach to meeting the health care needs of adults with developmental disabilities provides a service model that will benefit adolescents and young adults, as well.

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Joining Ethnic Sensitivity with Family-Centered, Community-Based Care

by Peggy Mann Rinehart

Health care practitioners need to be conscious of cultural beliefs and values that influence a family's perspectives on illness and disability. The ease with which physicians and other practitioners successfully incorporate ethnic and cultural differences in their work will depend on:

- The cultural or ethnic background of the health care professional.
- The sensitivity and competence of the health care professional to deal with cultural and ethnic differences.
- The degree of conflict between the family's values and view of care and treatment, and the use of the services of health care professionals.
- The influence of racism, poverty, and political powerlessness that accompanies cultural and ethnic identification.
- Language and the strength of cultural and ethnic identification.

Cultural sensitivity and the competence to deal with ethnicity can prevent miscommunication and alienation. Families can build trust with a physician who they believe understands their values. For example, a direct style of addressing the family and confronting the issues would be viewed as non-condescending by many Asian Americans and African Americans. However, many Native American families would perceive directness to be "rude", and many Mexican American families might find it to be "threatening."

Similarly, treatment that is prescribed needs to respect family cultural or religious beliefs. Surgery may not be a good option if a family has a cultural taboo against cutting someone open. Furthermore, if a child's condition is not a problem for the family, it is unlikely they will agree to any kind of treatment; there is no reason to repair something that is not broken. For example, a Native American family may reject the thought of moving a "disabled" child to an institution for either care or therapy. They might simply believe that the child functions perfectly for that child.

Physicians should understand how their own cultural identity and their own family values can affect their patient and the family. The physician's cultural perspective can affect a family's reaction to:

- Issues of trust and shared confidences.
- Openness in discussing problems.
- Value placed on the practitioner's medical opinion.
- Willingness to accept treatment or advice.

Hesitancy in any of these areas may be based on the family's cultural values or biases, and should not be mistaken for ignorance or lack of concern.

There are many ethnic and cultural practices that need to be considered on a situation-by-situation basis. They include the following:

- The implications of the suggested treatment for the family (such as long-term separation).
- The possibility that some topics should not be discussed with a parent who is not of the same gender as the physician.
- The cultural curative practices that the family may believe are more legitimate than modern or scientific practices.

Primary care providers should be aware of, and responsive to, our society's diverse cultural heritage. They need to recognize family values that may include "at home" treatment and cultural healing techniques and not assume neglect. A physician who is aware of the broad ways culture impacts how families perceive illness and disability can approach discussions and treatment suggestions in ways that families find nonthreatening and acceptable. Indeed, when physicians take the time to think through the implications of their recommendations, they foster trust. The greater the trust the family has in the physician, the more likely they are to implement the physician's suggestions.

Parents and physicians share a common bond: the child's well-being. For the sake of the child, health care providers need to understand their own prejudices, beliefs, and behavior, and how these fit or do not fit with the family's beliefs. Ethnic sensitivity and competence, and family-centered, community-based care require this kind of collaboration.

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Partners in Policymaking: Training Policy Advocates

by David Hancox

Partners in Policymaking is a nine-month education and training program for parents of young people with developmental disabilities and for adults with disabilities. It is designed to provide participants with the information, training, resources, and skills they need to obtain the best available services. The overall goal is to reach a productive partnership between people traditionally underserved and unserved who need and use services, and those people who make public policy.

The participants in Partners attend eight two-day sessions over a nine month period. Each session is devoted to a specific issue that relates to critical disability policy or service delivery. Topics include *History of the Parent and Independent Living Movements, Perceptions of Individuals with Disabilities; Inclusive Education; State Legislative Issues and Processes; County Government and Service Delivery; Severe Physical Disabilities and Technology; Supported Living, Family Supports, Supported Employment, and Working with the Minnesota Congressional Delegation; Community Organizing; Conflict Resolution; Negotiation Skills;* and *Facilitating Effective Meetings*. Each of these sessions is supported by faculty who are identified and selected for their philosophical compatibility. The combined sessions total approximately 128 hours of active instruction, with information and interactive role play reinforced with homework assignments and between-session readings. Partners also provides participants with the opportunity to meet and talk to international and national leaders in the field of developmental disabilities.

The growing critical debate surrounding health care reform is of obvious and significant importance to individuals with disabilities and their families. To be successful participants in the debate, we need more than ever to be seen as inclusive members of the community who need and use these services. In other words, what affects us, affects everyone. Partners in Policymaking responds to this need by providing competency-based education and training that intentionally prepares participants to interact and communicate with their public officials in an effective manner. In the sessions *County Government, State Legislative Issues and Processes,* and *Working with the Minnesota Congressional Delegation*, Partners provides instruction on how to draft and deliver effective testimony and, through role play activities with actual elected officials, offers significant opportunities to practice the skills necessary to conduct effective office visits related to specific issues. Participants are also given strategies for effective letter writing, phone calling, response to action alerts, and development of rapport with Congressional staffers.

Effects of the education and training techniques employed by Partners in Policymaking have been significant. Two-hundred ten enrollees in the Minnesota program between 1987-92 completed pre- and post-training surveys that revealed increased levels of advocacy/activism in response to specific disability related issues (see table).

Partners in Policymaking Outcomes (% in activity)

	Pre	Post
• Visits to legislators	31%	59%
• Phone calls to public officials	35%	79%
• Testimony to public hearings	13%	33%
• Letters to public officials	31%	79%
• TV/radio programs	10%	22%
• Parent group presentations	27%	43%
• Conference presentations	19%	43%
• Appointment to commission	34%	73%

Graduates and participants from the over 35 Partners programs across the country can tell stories of personal success in influencing policy. One graduate of Minnesota's Partners project, Sue Swenson, has delivered testimony to the U.S. Senate Subcommittee on Disability Policy and to committees of the Minnesota Legislature. In Iowa, Governor Terry Brandstad's intent to veto legislation that would create public support for personal attendant services was met with a swift and organized response from graduates of the four-year-old Iowa Partners in Policymaking program. At the center of the activity was Carl Gobb, a young man in his mid-20s with muscular dystrophy who had provided testimony to the Legislative committee that sponsored the legislation. He and others responded quickly and efficiently to the governor's resistance and flooded his office with more than 200 phone calls supporting the legislation. In Pennsylvania, the current Partners participants recently completed a letter writing campaign to both state and congressional elected officials addressing their personal concerns about health care reform.

Partners in Policymaking participants are taking an active role in the health care debate by addressing their concerns to, and influencing policy decisions of, elected officials. They will continue to exert their newly realized political power as a significant constituency group that represents a portion of the 42 million Americans with disabilities.

David Hancox is Director of the Minnesota Partners in Policymaking program. The program is administered by the Minnesota Institute of Public Health, Anoka, with support from the Minnesota Governor's Planning Council on Developmental Disabilities. FFI call (612) 427-5310.

Health Care Reform: The Impact on Persons with Disabilities

by Anne L. Henry

The shape of our future health care system is being debated on both the state and national levels. This debate is extremely important to everyone, including youth and young adults with developmental disabilities. Many people with disabilities require more than the average amount of health care and often need specialized services. In addition, many necessary community support services such as personal care assistance and home and community-based waivered services are funded with public dollars. The results of the current debate on how to reform our health care system will have a very significant impact upon the quality of life for persons with disabilities.

The Dilemma

In order to understand the various aspects of the health care debate on the national and state levels, it is necessary to focus on the two contending forces that have led to the push for health care reform: (1) an effort to improve health care including health coverage for uninsured persons, and (2) cost containment. The struggle to arrive at an agreeable health care reform plan is embodied in trying to achieve two seemingly contradictory goals: improve health care coverage while keeping costs down.

The need to improve health care coverage is propelled by the fact that 37 million Americans are uninsured. Health coverage for persons with severe disabilities is even worse: 43% or 10.5 million Americans with severe disabilities lack private health care coverage. Lack of health care coverage translates into bankruptcy due to high medical bills, delays in obtaining needed health services and, for many, impoverishment in order to qualify for government paid health care. The result of this significant lack of health care coverage is that when people without coverage do need care and are treated in hospital emergency rooms, costs are shifted to those who have coverage. In other words, health care providers have to make up the cost of uncompensated care by charging more to those who have coverage. As more people become uninsured, this escalating cost shift is born by employees, employers, individuals, and the government. These payors of health coverage are in turn pressing for cost containment.

Universal Coverage

To expand health coverage to those uninsured in our society will require increased dollars. Where will the money come from? This question is at the heart of the debate over health care reform. In order to obtain funds to cover everyone, several proposals for reform rely upon requiring everyone to have coverage, thus increasing the dollars paid into the health care system and reducing uncompensated care. Persons with disabilities and advocates generally support requiring universal coverage (health coverage for all) because the costs of health care are spread out over more people and thus are more affordable. There are several routes to universal coverage now under consideration:

- An **Individual Mandate** would require individuals to have health insurance whether paid by individuals themselves, by employers or by the government, which would subsidize low-income individuals. The Chafee Plan in Congress provides for universal coverage through an individual mandate.
- An **Employer Mandate** would require that all employers pay a specific percentage of their employees' health coverage. The Clinton Plan requires that employers pay 80 percent of the cost of health coverage.
- The **Single Payer System** achieves universal coverage by collecting broad-based taxes, such as payroll taxes, income taxes and so-called "sin" taxes (tobacco, alcohol) and uses the tax proceeds to pay for health care for everyone in the country.

One way or another, the cost of health care must be spread across a broader base in order to obtain the increased funding necessary to cover the uninsured. Some health reform plans do not include universal coverage, but instead propose reforms to make insurance purchase easier, simplify claims forms, and reduce government health care programs such as Medicaid and Medicare. Universal coverage is important if real improvement in health coverage is to be achieved.

Purpose of Health Care Services

A second very significant issue affecting youth and young adults with developmental disabilities in the health care reform debate is the definition of "medically necessary care" or "appropriate and necessary health care." In other words, for what reason or purpose will health care services be provided and covered. Health services are often provided to "fix" a health problem or restore the patient's health. However, many individuals with disabilities need health services that may not result in recovery, but instead improve the

functioning of the person while not "curing" the disability or chronic illness.

The dangers for persons with disabilities in the definition of necessary health care can be seen by examining Minnesota's health maintenance organization (HMO) definition of medically necessary care. The definition provides that medically necessary care (a) restores or maintains the enrollee's health or (b) prevents deterioration of health or (c) prevents the reasonably likely onset of a health problem or detects a problem. This definition does not allow the coverage of health services that improve health or establish function. For persons with congenital disabilities, who are born without the ability to walk or to communicate, services that improve their health or establish a needed function are crucial.

Increasingly, Minnesota's HMOs are refusing coverage for ongoing maintenance therapy if an individual is not "rehabilitative," or is not expected to recover or be restored. Surgery or therapy to allow a young person to walk or bear weight is an extremely important health service that must be covered by any health care reform plan. This issue deserves ongoing attention from persons with disabilities and chronic illnesses. Any health care reform package that does not cover health services that improve or establish function will discriminate against persons with disabilities.

■ Benefit Set

The benefits to be included in a health care reform benefit set must include health services needed by persons with disabilities and chronic illness. Thus far, proposals for a benefit set have limited many services needed such as therapies (limited to 60 days post-injury), home care, and mental health services. Persons with disabilities and health care providers must be prepared to describe services needed and the health outcomes resulting from the services in order to justify coverage of those services.

■ Dispute Resolution

Because the choice of health care provider may be limited due to reliance on managed care arrangements, responsive grievance mechanisms are necessary to assure that needed health services are provided in a timely manner. There is much concern that the managed care entities that get a lump sum payment to provide health care have a financial incentive to provide as little care as possible. Financial incentives to underserve can have a detrimental impact on those with chronic illness or disability unless grievance processes assure proper decision making when disputes arise. Whatever the health service delivery structure, a strong dispute resolution mechanism must assure that an independent fact finder can make a timely decision when there is an immediate need for the disputed health care service.

■ Long-Term Care

Long-term care services such as personal care assistance, group homes, and nursing home care are extremely important for persons with disabilities or chronic illness. Inclusion of long-term care services in national health care reform would be costly and will happen only if there is an outpouring of citizen pressure on Congress to do so.

In addition to the issue of inclusion of long-term care in a national health reform package, the connection between acute care health services and the need for long-term support and assistance is not reflected in most proposals at the federal level. For instance, ongoing therapy services for an individual with physical disabilities will improve the person's functioning and reduce the need for assistance from others, but more and more health plans are refusing to cover such services. Another example is the importance of durable medical equipment and assistive technology in improving lives of persons with disabilities by increasing independence.

Public dollars, not private insurance or HMO funds, pay for long-term care (residential and nursing home services) and community support costs. These public costs and the incentive to reduce these costs by improving the functioning of persons with disabilities should be considered in the health care reform debate. The inclusion of long-term care services will help shift the focus to maximizing independence for persons with disabilities, an important goal of a reformed health care system.

■ What Individuals and Families Can Do

There are a growing number of health care reform plans being debated in Congress. The plans differ on whether and how universal coverage is achieved, how required benefits are decided upon, whether coverage of long-term care is included, and how the plans are financed. All of the federal plans now under consideration are in a state of flux. In order to stay abreast of proposed changes, it is necessary to follow daily updates through newspapers, radio and television news reports, and to connect with disability advocacy groups active at the national level. To assure that policymakers fully understand the issues involved, persons with disabilities or chronic illness, their families, friends, and health care providers must be informed and active at both the state and national levels. Our United States Senators and Representatives must hear from young people with disabilities and their families on the need for comprehensive health care reform, including long-term care services.

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Family Voices: Speaking Out on Health Care Reform

by Polly Arango

What is Family Voices? Family Voices is a grassroots network of families and professionals speaking on behalf of children and youth with special health needs during health care reform. We organized Family Voices in December, 1992, to make sure that our children and our families would be part of the development of health care reform, whether in our states or in Washington, D.C. We are families from throughout the United States who have children with special health needs. We are also caregivers, professionals, and friends whose lives have been touched by our children and families. We are a diverse group, representing a wide variety of children, health conditions, families, and communities. Our concern for children and youth brought us together. The families who founded Family Voices are also parents who have developed family support networks and organizations. We have led local, state, and national efforts to improve the health and education systems that serve our children. We have forged important partnerships with policymakers and professionals in our communities and states, and at the national level.

> As the debate on reform continues, there are steps that families of young people with disabilities can take to make their voices heard.

A recent study (Newacheck et al., 1994) indicates that about 15% of all children (or 9.8 million) have a chronic health condition. Of those, about 3.8 million children have some limitation on their activity, while about 326,000 have a disability that precludes them from performing a major activity of daily life. Roughly 86,000 have limitations in three major activity areas. These young people - our children - with special health needs are first and foremost children who have the right to grow up with their families, in their communities, secure in the knowledge that they are unconditionally loved and cared for. They require the same things that all children need - a chance to develop and fulfill the promise of their own lives. However, unlike most children, our children also have challenging health conditions. Some have physical or mental disabilities, others live with a chronic health condition, and many present a brief but life-threatening medical problem. Some need only an accurate diagnosis and routine monitoring; others need life-sustaining technology, treatment, and medicine for a lifetime. All have an impact on their families, health care providers, school systems, and communities. It's also important for us to understand that our children will grow into adults and that health care reform must support the transition from the pediatric health world into the adult health care system.

Many national groups focus on particular childhood illnesses or populations. Others represent children and adults with disabilities. Until Family Voices was formed, there was no national organization working on health care reform from the perspective of families and their children with special health needs. Family Voices believes that children with special health needs face common problems caused by fundamental inadequacies in our health care system. We do not support any specific health care reform plan. Instead, the role of Family Voices is to advocate for the inclusion of a set of basic principles in every health care reform proposal. Those principles are:

- Universal coverage and universal access to health care, regardless of age, health condition, employment status, family income or location.
- Comprehensive and affordable benefits.
- Health care that is family-centered, community-based, and supportive of the partnership between families and health professionals.

Family Voices brings together family expertise and commitment from around the country in order to:

- Shape health care reform at local, state, and national levels.
- Support a Family Voices national network with volunteer coordinators in every state that provides accurate, timely information to families and ensures that policymakers have access to reliable information from families who experience the inadequacies of our health care system daily.
- Use the expertise within our grassroots - hundreds of families in every state - to inform national dialogues and to share wisdom across state lines.
- Serve as a clearinghouse that collects information from a wide variety of sources. We develop and distribute working papers, bulletins, and information sheets to help all of us stay informed about health care reform.
- Form partnerships with professionals, and with other state and national organizations, to make sure the voices of families are heard and our children's needs are met.

So, how does health care reform look at this point? First of all, we believe that there is a health care crisis and that health care reform must take place because all families, even those who have good health coverage now, are in jeopardy.

We also believe that health care reform of some kind will pass Congress by the fall of 1994, before members of Congress go home to run for re-election. So we want to make sure that health care reform includes the kinds of health services that our children require. Many plans have been introduced into Congress, but the plan most talked about and the centerpiece for congressional debate seems to be the Clinton Plan. Last fall, about 50 of our member families analyzed the Clinton Plan, and we shared that analysis with our members. Our families applauded President Clinton for developing a plan that includes universal coverage, a good benefits package for most families, and affordable premiums. On the other hand, families viewed with alarm several aspects of the plan. For example, its restrictions on many rehabilitation services to those needed only as a result of illness or injury, or only to restore function; some limits on medical equipment; the strict eligibility criteria in long-term care (also called home and community-based care) that excludes many of our children; the costs to families of long-term care; and the state options for services in long-term care. Most other plans lack the good qualities of the Clinton Plan and share its shortcomings. Family Voices is working with advocates from the disability and child advocate communities to ensure that any health care reform legislation being considered in Congress includes the health care services that our children need.

As the debate on reform continues, there are steps that families of young people with disabilities can take to make their voices heard:

- Recognize that there is a health care crisis and that we need reform.
- Learn all you can about state and national health care reform measures.
- Tell your health care story to your Representative, Senator, state legislator, the government affairs person at your local disability organization.
- Look them in the eye and extract from them a promise that they will not support any reform legislation that does not include universal coverage and access, comprehensive and affordable benefits, and health care that is family-centered and community-based.
- Hook up with a local advocacy organization or Family Voices to make sure that your voice is heard!

Polly Arango is Co-Founder of Family Voices, Algodones, New Mexico. FFI call (505) 867-3159.

Reference: Newacheck, P.W., Hughes, D.C., McManus, M.M., Perris, J.M., Valdez, R., & Fox, H.B. (1994). *Meeting Children's Long Term Care Needs Under the Health Security Act's Home and Community-Based Services Program.* San Francisco: Institute for Health Policy Studies, University of California.

Sexuality, continued from page 5

their social lives. Those whose disabilities are severe may progress only in tiny increments toward a fully interactive social existence. But, whether progress is rapid or at a snail's pace, a teen will physically mature into an adult body. Thus, there is little difference between people without disabilities and those with disabilities as to the kind of knowledge and skills they need to express their sexuality in socially responsible and self-enhancing ways. The greater difference lies in how that information is learned, how long it takes to learn it, and how much supported social opportunity is available for practicing social skills. They need permission to become fully adult.

Adults can provide a great deal of assistance to help teens enjoy the fruits of full adulthood. They can offer information about sexuality in age-appropriate ways. They can advocate for sexuality programs that begin early in school life and for school or agency related social activities. However, they will often have to do more. Adults can create social opportunities for teens to get together with their friends. They can encourage visits to each other's homes for parties or just for low key "hangin' out." Because young adults with disabilities need more trials to become confident and socially adept, a non-threatening setting and a regular group of friends in that setting is an ideal place to practice social skills. Adults may have to help with transportation, facilitate telephone arrangements, and become allies with other parents or adults for many years longer than parents of individuals without disabilities - at least until social independence is reached or until community supports supplant family as a social facilitator or resource. Finally, families must be willing to recognize that teenagers are no longer children, despite the areas where teens and young adults may still be dependent upon adult supervision.

As individuals with developmental disabilities move into their adult lives, the role of sexuality education and skills becomes increasingly important to their quality of life. Education protects them from the ravages of sexual abuse and sexually transmitted diseases and, at the same time, opens a window of opportunity to greater physical, mental, social, and spiritual wellness.

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Print and Media Resources

■ Health Care

- **Children's Health Issues**. A newsletter for families and health care providers containing information on health needs and health care of children and youth with disabilities. Available from the Center for Children with Chronic Illness and Disability, University of Minnesota, Box 721, Minneapolis, MN 55455 • (612) 626-4032/(612) 624-3939 (TDD).

- **Speak Up for Health: A Handbook for Parents of Teens with Chronic Illness or Disabilities** (1993). By PACER Center. This guide addresses: the impact of chronic illness or disability on adolescent development, communicating with health professionals, self-advocacy in health care, health care financing, and adolescent sexuality. Available from PACER Center, 4826 Chicago Ave. S., Minneapolis, MN 55417 • (612) 827-2966.

- **Speak Up for Health Videotape**. In this 15-minute program (closed captioned) young adults discuss the value of independence in health care. Their parents, who recognize and support the need for knowledge and independence in health care, share their own perspectives on "letting go." Available from PACER Center, 4826 Chicago Ave. S., Mineapolis, MN 55417 • (612) 827-2966 (Voice/TDD). Available for purchase or rental.

- **HIV & AIDS Prevention Guide for Parents**. By M. Lerro. Topics in this booklet include *What Parents Should Know About HIV/AIDS and Mental Retardation, What Parents Should Teach About HIV and AIDS, How to Teach Your Daughter or Son About HIV/AIDS, Illustrations and Demonstrations, Teaching Your Daughter About Safer Sex, Making Sure Other People Teach the Facts,* and *Resources*. Available from The Arc, National Headquarters, 500 E. Border St., Suite 300, Arlington, TX 76010 • (817) 261-6003/ (817) 277-0553 (TDD).

- **Quality Health Care for People with Developmental Disabilities: A Guide for Parents and Other Caregivers** (1988). This guide provides information and strategies to assist parents and other caregivers in recognizing, obtaining, and advocating for high quality health care for children and youth with developmental disabilities. Available from Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455 • (612) 624-4512.

- **Chronic illness and disability in adolescence** (1991). By G. Geber, and N. Okinow. In *The Health of Adolescents*, W. Hendee and B. Wilford (Eds). San Francisco: Jossey-Bass Publishers.

■ Transition

- **Making Choices for Community Living: A Guide for Self-Planning** (1993). By M. Malcolm Jeffreys and P. Sproul. This book is designed to be used by individuals with developmental disabilities as they plan and make decisions about living in the community. Available from Windsor Community Living Support Services, 242 Lauzon Rd., Windsor, Ontario N8S 3L6 • (519) 974-4221.

- **IMPACT: Feature Issues on Transition** (1990, 1992). These two newsletters profile programs and strategies addressing all aspects of life for youth in transition from high school to adult community living. Available from Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455 • (612) 624-4512.

- **Begin the Between: Planning for the Transition from High School to Adult Life** (1992). This workbook guides students with disabilities and their families in developing a comprehensive transition plan based on their exploration of the student's skills, interests, and future goals. Available from PACER Center, 4826 Chicago Ave. S, Minneapolis, MN 55417 • (612) 827-2966 (Voice/TDD).

- **Transition to Adult Life for Individuals with Disabilities: Print and Media Resources** (1992). A guide to transition-related print and audio/visual materials for use by those who work with youth /young adults, and by families. Available from Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455 • (612) 624-4512.

■ Sexuality

- **Sexuality education resources** for youth with disabilities are available from:

  James Stanfield and Company
  P.O. Box 41058, Santa Barbara, CA 93140 • (800) 421-6534. Free catalog.

  VIDA Publications, P.O. Box 331, Willow Street, PA 17584-0031 • (717) 786-8000. Free product list.

- **Changes in You for Girls** and **Changes in You for Boys** (1991). By P.C. Siegel. These two booklets discuss physical, emotional, social, and sexual changes of puberty. Written in simple clear language for youth to read, with life-like illustrations. Available from Planned Parenthood of SE Pennsylvania, Resource Center, 1144 Locust St., Philadelphia, PA 19107 • (215) 351-5590.

Strategies, continued from page 1

- **Encourage young adults to begin to assume responsibility for their own health with appropriate supports.** Supporting the development of choice and independence in personal health habits and daily living are part of the foundation for health and wellness. Recognition of the sexuality of adolescents and young adults with developmental disabilities is crucial, including the provision of developmentally appropriate family life and sexuality education, which addresses the prevention of HIV infection and other sexually transmitted diseases.

- **Recognize and facilitate, as feasible and appropriate, developmentally and age-appropriate privacy.** This is an important part of helping young adults assume more responsibility for their own health, particularly in their relationship to health care providers. Some providers will need education and encouragement from families to learn to communicate more directly with the young adult with developmental disabilities, which may include learning more about someone's augmentative or other system of communication as well as learning how to structure choices and information in a manner that is accessible to the young person.

- **Pay attention to proper body mechanics and positions for adolescents and young adults who utilize adaptive equipment and assistive technology.** The desire and need for functionality and independence at present should support, not damage, bodily structures, preserving health for the long term.

- **Address guardianship issues in planning for adult health services.** Procedures vary from state to state, but the clear identification of who may give health care consents eases the transition to a new health care provider or setting. For individuals under limited or partial guardianship, it is important to clarify in which areas the individual may make decisions. For all adolescents and young adults, whether they have parents as their guardians because of age or abilities or they are their own guardians, it is important to stress the right of individuals and the importance of access to appropriate information to understand their own health and treatment options.

- **Maintain a complete and portable health history.** This is very helpful in making the transition to adult health care. The history should track and document age appropriate screenings and immunizations as well as screenings that are targeted to the individual's particular disabling condition, and should emphasize health promotion.

- **Include health and wellness issues/concerns in formal plans.** This includes the Individual Education Plan (IEP), the Individual Transition Plan (ITP), and the Individual Written Rehabilitation Plan (IWRP) for adolescents and young adults.

- **Educate physicians and other health care providers.** They may need to know more about transition in other areas of the young adult's life, including work and independent living.

- **Educate and involve health care providers as allies.** Utilize them in advocating for the full range of supports desired by people with disabilities and their families.

As the nation debates the shape of our future health care system, young people and their families can take steps to support their individual health and well-being. For too long disability has been equated with illness; being disabled is not the opposite of being well. And the transition to adulthood and adult health care services is an important juncture in the continuing pursuit of healthy lives for people with developmental disabilities.

Deborah Spitalnik is Executive Director of the University Affiliated Program of New Jersey, and Associate Professor of Clinical Pediatrics and Family Medicine at the University of Medicine and Dentistry of New Jersey - Robert Wood Johnson Medical School, Piscataway. Anne E. Brady is Primary Health Care Coordinator at the Family Practice Center, Inc. of St. Peter's Medical Center, New Brunswick, New Jersey. Robert C. Like is Associate Professor of Family Medicine and Director of Adult Primary Health Care, at the University of Medicine and Dentistry of New Jersey - Robert Wood Johnson Medical School, Piscataway. FFI call (908) 235-4447 / (908) 235-4407 (TTY).

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early dependency, the well-documented problem of "learned helplessness."

Overall, the residents have greatly appreciated the experiences provided in the rotation. Many cite it as their best exposure to "life beyond the clinic door" and their best opportunity to understand "normal" functioning for families with children who have disabilities.

Peter Blasco is a developmental pediatrician and Associate Professor with the Center for Children with Chronic Illness and Disability, University of Minnesota, Minneapolis. FFI call (612) 626-4032.

Note: Portions of this article were extracted from material published in *Springboard*, the newsletter of the Center for Children with Chronic Illness and Disability. See Rinehart, P.M. (1992). Resident training: building knowledge and sensitivity. *Springboard 1* (3): 1-2, 1992; and Blasco, P. (1993). Beyond the purely medical. *Springboard 4* (#1): 8-9.

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- Recovering and Proud: Ricky's Story
- *School Health Services*: Supporting Student Health Needs
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- Resources

IMPACT: Feature Issue on Health Needs of Transition-Aged Youth September 1994

Managing Editor: Vicki Gaylord
Issue Editors: Pat Tommet, Barbara J. Leonard, Ceci Shapland

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